

# Family Partnership

## GET IN THE GAME

### 2009 Parent & Caregiver Retreat

December 4-5, 2009

The Inn at Grand Glaize • Osage Beach, Missouri

Are you tired of  
striking out when  
trying to get supports  
and services for your  
child with special  
health care needs?

OR

Have you been  
benched more times  
than you can count?

If so then don't miss  
this year's retreat  
where we will get you  
in the game!

Family Partnership is excited to host their 9th annual Parent & Caregiver Retreat "Get in the Game," an event designed especially for Missouri parents, legal guardians and caregivers (18 and older) of children, youth and young adults with special health care needs.

This year's Retreat offers participants, new and seasoned, the ability to stride over the hurdles of life when caring for a child, teen or young adult with special health care needs:

- Personal leadership development
- Access to resource information
- A chance to network with others
- Opportunities to provide input to improve programs and services affecting their family

Friday evening will begin with a nice dinner while meeting new friends or catching up with those from last year followed by an interactive game for all participants. Saturday will be filled with information and education, ending with the chance for participants to win fabulous prizes!



## **Family Partnership's 2009 Parent & Caregiver Retreat**

The Family Partnership provides information and support to children and youth with special health care needs and their families. These individuals are also given the opportunity to network with each other through various settings including regional and statewide meetings. Family Partnership members include individuals with special health care needs as well as their parents, legal guardians or siblings. SHCN utilizes information from Family Partnership members to enhance the relationship between SHCN and the individuals and families they serve. The Family Partnership is administered through an SHCN contract with the Miller County Health Center.

For more information: [www.dhss.mo.gov/FamilyPartnership](http://www.dhss.mo.gov/FamilyPartnership)

### **GET IN THE GAME**

#### **Friday December 4<sup>th</sup>**

3:00 pm	<b>Hotel Check-in</b>
5:00-7:30	<b>Retreat Registration Check-in</b>
5:00-6:45	<b>Network Café</b> —Catch up with friends from past Retreats or make new ones while enjoying a fabulous dinner!
7:00-7:15	<b>Retreat Kickoff</b>
7:15-8:30	<b>"Get in the Game"</b> —this interactive event will be sure to leave you with new friends and resource information.
8:30	<b>Adjourn for the evening</b>

#### **Saturday December 5<sup>th</sup>**

7:30-9:00 am	<b>Network Café Breakfast</b> —chat with other participants while enjoying breakfast or a cup of java!
9:00-9:15	<b>Welcome &amp; Presentation of Family Partnership</b>
9:15-10:30	<b>Kathie Snow</b> <b>DISABILITY IS NATURAL AND OTHER REVOLUTIONARY COMMON SENSE:</b> Yes, like gender, ethnicity, and other traits, disability is one of many natural characteristics of being human! What can happen when we deconstruct disability, use People First Language, and focus on people's strengths and abilities? Awesome change is possible when we think differently and talk differently!
10:30-10:45	<b>Break, Hotel Checkout and Exhibitor Visits</b>

## Saturday December 5<sup>th</sup> (cont.)

10:45-11:35

<b>Medical Home</b> <b>Kenneth Thomas, MD</b> <b>Director of Special Health</b> <b>Care Needs</b> <b>Children's Mercy Hospital</b>	<b>Transition</b> <b>George Gotto</b> <b>UMKC-IHD</b>
<p>This presentation will include information about medical home/coordinated care. This session will provide caregivers with strategies to advocate for coordinated care as well as gain a better understanding of the benefits of coordinated care from their healthcare provider.</p>	<p>As a result of improving technology many patients with chronic pediatric conditions are now living well into adulthood. We will discuss: 1) Things teens and young adults with SHCN should be able to do; 2) Developing an adult health care team; and 3) Financing adult health care.</p>

11:35-12:00

**Break, Hotel Checkout and Exhibitor Visits**

12:00-12:50

**Network Lunch Café—Kathie Snow Creative Collaboration**

Waiting lists, budget cuts, too many people to serve! Even under the best of circumstances, the service system and disability organizations cannot meet the needs of all. But when disability and non-disability organizations collaborate, extraordinary outcomes are possible.

12:50-1:00

**Break and Exhibitor visits**

1:00-1:50

<b>Representative Jeff</b> <b>Grisamore</b>	<b>Disaster Preparedness</b> <b>Vicky Davidson, M. Ed.</b>
<p>Representative Jeff Grisamore has quickly become a leader in the Missouri General Assembly for disabilities advocacy. He will present on disabilities related legislation and transformation strategies for the State of Missouri. He is pursuing integrated and comprehensive strategies to transform disabilities funding and services in Missouri.</p>	<p>Emergencies and disasters take a huge toll on individuals, which include families with children with disabilities. This session is aimed at improving the personal preparedness of people who have disabilities and their family members. It is important to attend to learn about personal preparedness as well as how to become involved at all levels of emergencies and disasters.</p>

1:50-2:00

**Break and Exhibitor visits**

2:00-3:00

**Evaluations, Prizes & Wrap-up**

\*Speakers may be subject to cancellation at any time and without notice due to unforeseen circumstances.

# Family Partnership's 2009 Parent & Caregiver Retreat

## WHY SHOULD I ATTEND?

At the Retreat you will have the opportunity to:

- Network with others who may be facing the same issues as you.
- Learn area resources to help you and your family.
- Enhance your leadership and advocacy skills!
- Possibly win one of several fabulous prizes to be given away!
- Receive Friday night's hotel accommodations & all meals FREE plus a \$100 stipend to help with childcare, gas or other expenses required to attend. *(Stipends are one per family and mailed within 30 days of the Retreat).*

## WHAT IS THE REGISTRATION FEE?

A **refundable registration fee** of \$50 per couple or \$25 per person is due at the time of registration. This fee guarantees your hotel accommodation, meals and seating at the Retreat. Your check or money order will not be processed for payment **unless you fail to arrive without notice** *(see what if I need to cancel?)*. When you arrive at the Retreat, your check or money order will be returned back to you.

## HOW DO I REGISTER?

Complete the attached registration form and return it with your payment (check or money order only) payable to Miller County Health Center and mail it with your completed registration form to:

Miller County Health Center—Attn: Lucretia  
PO Box 2  
Tuscumbia, MO 65082

## WHEN IS THE REGISTRATION DEADLINE?

While the registration form and fee must be **received** by Friday, November 6, 2009, limited seating and hotel accommodations are available for the Retreat. We anticipate the Retreat to fill quickly and encourage you to submit your registration form as soon as possible. Registration forms submitted after that date will not be guaranteed hotel accommodations or seating space at the Retreat. If a waiting list develops, registrations will be filled in the order they are received. If this occurs, you will be notified as to the status of your registration.

## WHAT IF I NEED TO CANCEL?

We understand it's a challenge for families who have children, especially those with special needs, to plan for events like this and attendance can sometimes be decided at the last minute. If you should need to cancel your registration entirely, your cancellation request **must be received in writing** *(e-mail, fax or US Postal mail—no phone calls)* **by 12pm Thursday, November 12, 2009**, to Lucretia Huff at [huffl@lpha.mopublic.org](mailto:huffl@lpha.mopublic.org) or fax (573) 369-2350 in order to receive a full refund of your registration cost. **NO** refunds will be made for cancellations received after this date.

## CAN I BRING MY CHILD(REN)?

Family Partnership is dedicated to providing a relaxing, fun environment for parents & caregivers (18 and up) who may not have resources to get away often to escape the stressors of their everyday life. For this reason, we do not offer childcare but a stipend to help offset respite expenses. We ask that you not register anyone under 18 as a participant or bring them with you. Please respect this policy designed by experienced Retreat participants to enhance this unique experience.

Please fill out and return with your completed registration.

1. Have you attended the Family Partnership Parent and Caregiver Retreat in the past? YES NO

If so when? \_\_\_\_\_

2. Has your child or youth received services from the Bureau of Special Health Care Needs? YES NO

If you answered Yes, please list your Service Coordinator's name.

\_\_\_\_\_  
If you answered No, would you like to receive information regarding services through the Bureau of Special Health Care Needs? YES NO

3. Please list your child's medical condition.

\_\_\_\_\_  
\_\_\_\_\_

### GET IN THE GAME



---

#### Comments from previous retreat participants

--*Become a better advocate for my children.*

--*I have new found hope.*

--*Finding out there are other families who face the same issues.*

--*There are other alternatives to Guardianship.*

--*How to obtain a special needs trust.*

## Family Partnership's 2009 Parent & Caregiver Retreat

To register a guest, (spouse, partner or other adult family member) please copy this form as necessary. Please print or type.

Name: \_\_\_\_\_ Name for Badge: \_\_\_\_\_

Company Name (if any): \_\_\_\_\_

Mailing address: \_\_\_\_\_

City: \_\_\_\_\_ MO Zip: \_\_\_\_\_

Home phone: \_\_\_\_\_ Cell Phone: \_\_\_\_\_

Email address: \_\_\_\_\_

**Please check below on how we can make your Retreat experience more comfortable:**

- ☐ Accessible sleeping room with: \_\_\_\_\_ high riser \_\_\_\_\_ wheel-in-shower
- ☐ First floor sleeping room (the hotel is equipped with elevators)
- ☐ I'd like to room with: \_\_\_\_\_
- ☐ I'd like to room alone & have included a separate check/money order for \$35.00
- ☐ Diet \_\_\_\_\_ Diabetic \_\_\_\_\_ GlutenFree \_\_\_\_\_ Vegetarian \_\_\_\_\_ Other \_\_\_\_\_
- ☐ If any other accommodations are needed please contact Lucretia Huff at (866) 809-2400

**For Parents, Caregivers and Family Members:**

**Choose One Morning Session (10:45a.m.-11:35a.m.)**

- ☐ Medical Home—Kenneth Thomas, MD Children's Mercy Hospital
- ☐ Transition—George Gotto, UMKC-IHD

**Choose One Afternoon Session (1:00p.m.-1:50p.m.)**

- ☐ Representative Jeff Grisamore
- ☐ Disaster Preparedness—Vicky Davidson, M. Ed.

**Retreat Fees: (amounts listed are per person)**

Parent/Caregiver (refunded upon arrival)	\$25.00	
Family Member (refunded upon arrival)	\$25.00	
Single Hotel Accommodation (if rooming alone)	\$35.00	
Professional Speaker/Exhibitor Fees		
Dinner	\$20.00	
Breakfast	\$10.00	
Lunch	\$12.00	
Hotel Accommodations	60.00	
	Total	

**Please mail completed form with all fees by 11/06/2009 to:**

**Miller County Health Center—Attn: Lucretia, PO Box 2 Tuscumbia, MO 65082**



## Family Partnership's 2009 Parent & Caregiver Retreat



The Family Partnership's mission is to communicate, advocate, and network through a family and agency team-supported effort to enable individuals with special health care needs to reach their fullest potential throughout life.

### HOW DO I MAKE RESERVATIONS FOR MY HOTEL ROOM?

Room reservations will be made directly with the hotel by Family Partnership upon receipt of your refundable registration fee and completed registration form on a first-received basis. Accommodations are based upon double occupancy. If you are registering as a single participant and you know of someone that you'd like to room with let us know on your registration form. If you would simply prefer to room alone, single occupancy rooms are available for \$35.00. Separate payment must be made to Miller County Health Center and included with your registration form. If, however, you have a special need and require a single room, please contact Lucretia Huff at (866) 809-2400 ext 308 to arrange accommodations. All sleeping room are "non-smoking." The hotel will assess a cleaning fee of approximately \$250 to any guest who chooses to smoke anywhere on the hotel premises which is not designated for smoking.

**Rooms will be guaranteed for arrival no later than 6:00 p.m.** If you find that you will not be arriving before 6:00 p.m. on Friday and have not indicated this on your registration form, please call the hotel at (573) 348-4731. If you do not arrive before 6:00 p.m. without notifying us, rooms will be cancelled or given to another participant.

### Rooms for Saturday Night

If you would like to extend your stay to include Saturday night, please contact Lucretia at (866) 809-2400. The hotel has offered the participants of the Retreat to stay at the hotel an additional night for a rate of \$55.00 plus any taxes and fees.



The Inn at Grand Glaize

5142 Hwy 54

Osage Beach, MO 65065

[www.innatgrandglaize.com](http://www.innatgrandglaize.com)



**SHCN FAMILY PARTNERSHIP at  
MILLER COUNTY HEALTH CENTER  
PO BOX 2  
TUSCUMBIA, MO 65082**

**Need more information? Contact your Family Partner listed below or  
the Family Partnership Project Coordinator**



Family Partnership is a project for Missouri families of special needs individuals. The project is funded by the Maternal and Child Health Bureau Title V Block Grant and the Missouri Department of Health and Senior Services, Special Health Care Needs and is achieved by means of an agreement with the Miller County Health Center.

**Tracy Damario, Northwest Family Partner**

(KC and metro area, Sedalia, Marshall, Warrensburg, Maryville, & St. Joseph)

Email: [tsimmons8103@aol.com](mailto:tsimmons8103@aol.com)

Phone: (816) 213-8103

**Mamie Benson, Southeast Family Partner**

(Kennett, Poplar Bluff, Rolla, & Tyler)

Email: [mamielbenson@yahoo.com](mailto:mamielbenson@yahoo.com)

Phone: (573) 919-4143

**Beverly Woodhurst, Northeast Family Partner**

(St. Louis, Hannibal, Kirksville, Jefferson City, Moberly, Wayland, & Columbia)

Email: [shcnfamilypartner@yahoo.com](mailto:shcnfamilypartner@yahoo.com)

Phone: (573) 473-8873

**Kelly Bass, Southwest Family Partner**

(Springfield, Branson, Lebanon, Joplin, Camdenton, & Clinton)

Email: [klybass@yahoo.com](mailto:klybass@yahoo.com)

Phone: (417) 833-2349

**Lucretia Huff, Project Coordinator**

Email: [huffl@lpha.mopublic.org](mailto:huffl@lpha.mopublic.org)

Phone: (866) 809-2400 ext 308